



BILLING CODE: 4165-15

DEPARTMENT OF HEALTH AND HUMAN SERVICES

Health Resources and Services Administration

Discretionary Advisory Committee on Heritable Disorders in Newborns and Children

Notice of Meeting

In accordance with section 10(a)(2) of the Federal Advisory Committee Act (Public Law 92-463, codified at 5 U.S.C. App.), notice is hereby given of the following meeting:

NAME: Discretionary Advisory Committee on Heritable Disorders in Newborns and Children

DATES AND TIMES: January 16, 2014, 10:30 a.m. to 2:30 p.m.

January 17, 2014, 10:00 a.m. to 3:30 p.m.

PLACE: Virtual via Webinar

STATUS: The meeting is open to the public. For more information on registration and webinar details, please visit the Advisory Committee's website:

<http://www.hrsa.gov/advisorycommittees/mchbadvisory/heritabledisorders>

The registration deadline is Wednesday, January 8, 2014, 11:59 p.m. Eastern Standard Time (EST).

PURPOSE: The Discretionary Advisory Committee on Heritable Disorders in Newborns and Children (Committee), as authorized by Public Health Service Act (PHS), 42 U.S.C. 217a: Advisory councils or committees, was established to advise the Secretary of the Department of

Health and Human Services about the development of newborn screening activities, technologies, policies, guidelines, and programs for effectively reducing morbidity and mortality in newborns and children having, or at risk for, heritable disorders. Note: the Committee's recommendations regarding additional conditions/inherited disorders for screening that have been adopted by the Secretary are included in the Recommended Uniform Screening Panel and constitutes part of the comprehensive guidelines supported by the Health Resources and Services Administration. Pursuant to section 2713 of the Public Health Service Act, codified at 42 U.S.C. 300gg-13, non-grandfathered health plans are required to cover screenings included in the HRSA-supported comprehensive guidelines without charging a co-payment, co-insurance, or deductible for plan years (i.e., policy years) beginning on or after the date that is one year from the Secretary's adoption of the condition for screening.

AGENDA: The meeting will include: (1) the Nomination and Prioritization Workgroup's review on X-linked Adrenoleukodystrophy (ALD); (2) an update on Mucopolysaccharidosis type 1 (MPS-1) from the Condition Review Workgroup; (3) an update on the HRSA-funded Newborn Screening Technical Assistance Center; (4) a presentation on the impact of the rapid implementation of electronic health records on the Early Hearing Detection and Intervention State Programs; (5) an introduction to the HRSA-funded Long Term Follow-up Program; and (6) updates from the Committee's subcommittees and ad-hoc workgroups including Laboratory Standards and Procedures, Follow-up and Treatment, and Education and Training subcommittees. Tentatively, the Committee is expected to review and/or vote on whether to refer the ALD nomination to the Condition Review Workgroup. This vote does not involve a proposed addition of a condition to the Recommended Uniform Screening Panel.

Agenda items may be subject to change as necessary or appropriate. The agenda, webinar information, Committee Roster, Charter, presentations, and other meeting materials are located on the Advisory Committee's website at

<http://www.hrsa.gov/advisorycommittees/mchbadvisory/heritabledisorders>.

PUBLIC COMMENTS: Members of the public may register to present oral comments and/or submit written comments. All comments, whether oral or written, are part of the official Committee record and will be available on the Committee's website. Advance registration is required to present oral comments. The public comment period is scheduled for the morning of January 16, 2014. Written comments may be emailed to Lisa Vasquez at lvasquez@hrsa.gov by Wednesday, January 8, 2014, 11:59 p.m. EST. Written comments should identify the individual's name, address, email, telephone number, professional or business affiliation, type of expertise (i.e., parent, researcher, clinician, public health, etc.), and the topic/subject matter of comment. Individuals who wish to make oral comments are required to email Lisa Vasquez at lvasquez@hrsa.gov by Wednesday, January 8, 2014, 11:59 p.m. EST.

<https://www.blsmeetings.net/SACHDNC/index.cfm> To ensure that all individuals who have registered to make oral comments can be accommodated, the allocated time may be limited.

Individuals who are associated with groups or have similar interests may be requested to combine their comments and present them through a single representative. No audiovisual presentations are permitted. For additional information or questions on public comments, please contact Lisa Vasquez, Maternal and Child Health Bureau, Health Resources and Services Administration; telephone: (301) 443-1080; email: lvasquez@hrsa.gov.

FOR FURTHER INFORMATION CONTACT: Anyone interested in obtaining other relevant information should contact Debi Sarkar, Maternal and Child Health Bureau, Health Resources

and Services Administration, Room 18A-19, Parklawn Building, 5600 Fishers Lane, Rockville, Maryland 20857; telephone: (301) 443-1080; email: dsarkar@hrsa.gov.

More information on the Advisory Committee is available at
<http://www.hrsa.gov/advisorycommittees/mchbadvisory/heritabledisorders>.

Dated: December 23, 2013

Bahar Niakan

Director, Division of Policy and Information Coordination

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